



Pandasnetwork.org

January 30, 2015

**Insurance & Real Estate Committee**  
**SB 15 requiring insurance coverage for PANDAS in CT**

Dear Senator Crisco and Distinguished Members of the Insurance and Real Estate Committee:

I sincerely ask you to consider the passage of **SB 15 requiring insurance coverage for PANDAS in CT.**

I am the Executive Director of PANDASNetwork.org, a 501c3 organization that represents 4,000+ children and families afflicted by this pediatric disease. PandasNetwork.org is recognized as an Official Partner of the National Institute of Mental Health (NIMH) and the National Organization of Rare Disorders (NORD) amongst many others.

Since 2009 I have worked with various medical experts in determining the efficacy of the off-label use of IVIG in severe PANDAS cases and it has been found to be effective, safe and life-saving in hundreds of cases. Please allow expert testimony from the NIMH, Yale University and elsewhere to be considered in future assessments of IVIG necessity.

The average age of onset is between ages 4-10. Early treatment within the first year of onset cures the majority of children. Untreated the child will often struggle with lifelong neurological and psychological problems.

Without the potential of IVIG in severe cases, untreated children may remain sick for years and into adulthood. Families will incur financial costs potentially well into the hundreds of thousands – affecting social, medical, educational, and family systems.

On a personal note, my own child developed PANDAS in 2007 at the age of 7. My very healthy boy changed overnight after a strep infection—intense debilitating fears, tourette-like movements, obsessions, fatigue, confusion, and more. There was a tremendous toll on our family emotionally and financially as we searched for treatment. We healed him with a tonsillectomy, antibiotics and two (2) IVIG treatments. By age 10 he was symptom free and remains so now at age 15 years. He is a stable, intelligent, confident teenager!

Please consider, finally, that in our lives as adults we so many recalcitrant *illnesses and issues*. SB15 can *reverse tragic illness* and *stop potentially many social and economic problems* each of these families and the CT community as a whole will face without its passage.

Sincerely,

Diana Pohlman, Executive Director  
PandasNetwork.org

*Full Legal Name: P.A.N.D.A.S. Network.org, a non-profit to Cure Pediatric Acute Neuropsychiatric Syndromes, Inc.*